

Autism Spectrum Disorder Research Portfolio Analysis

Office of Autism Research Coordination (OARC), NIMH

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Introduction

- Since 2008, the Office of Autism Research Coordination (OARC), on behalf of the Interagency Autism Coordinating Committee (IACC), has conducted an annual comprehensive analysis of the autism spectrum disorder (ASD) research portfolios of major U.S. Federal agencies and private organizations.
- The intent of these analyses is to better inform the IACC and interested stakeholders about the funding landscape and current directions for ASD research.

Data Collection

- The most recent *Portfolio Analysis Report*, which covered 2011 and 2012, includes data from 12 Federal agencies and 8 private organizations.

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
<ul style="list-style-type: none"> Administration for Children and Families (ACF) Administration for Community Living (ACL) Agency for Healthcare Research and Quality (AHRQ) Centers for Disease Control and Prevention (CDC) Centers for Medicare & Medicaid Services (CMS) Department of Defense (DOD) Department of Defense (AF) Autism Research Program (ARP) Department of Education (ED) Environmental Protection Agency (EPA) Health Resources and Services Administration (HRSA) National Institutes of Health (NIH) National Science Foundation (NSF) Substance Abuse and Mental Health Services Administration (SAMHSA) 	<ul style="list-style-type: none"> Autism Research Institute (ARI) Autism Science Foundation (ASF) Autism Speaks (AS) Brain & Behavior Research Foundation (BBRF) Center for Autism and Related Disorders (CARD) Organization for Autism Research (OAR) Simons Foundation (SF) Southwest Autism Research & Resource Center (SARRC)

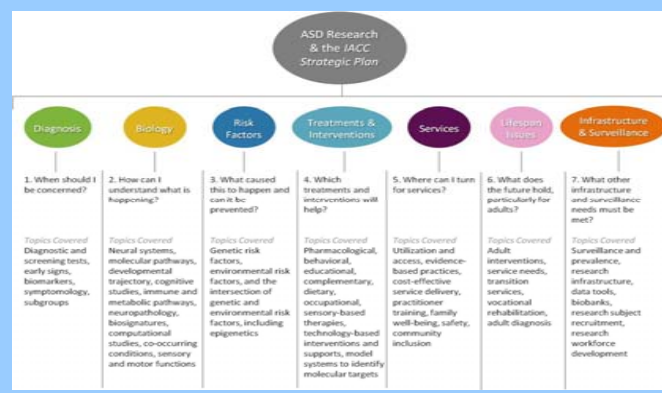
- Information collected on ASD research projects includes: **project title, grantees (PIs), funder, grantee institution, annual funding, award period, and project description.**
- The Portfolio Analysis examines the extent to which individual research projects align with two coding systems:
 - The **78 research objectives** laid out in the *2011 IACC Strategic Plan* for ASD Research (see middle panel). This enables tracking of the progress made towards achieving the goals set out in the *Plan*
 - OARC staff work with program officials at the different funders to assign the most appropriate objective code to each project that is reported.
 - Research **subcategories** which also fall under the seven key areas outlined by the *Strategic Plan* (see middle panel).
 - This internal OARC coding system organizes the projects into groups that share common elements or themes. This provides a complementary coding system which is very user-friendly and captures projects that do not align with specific objectives of the *Strategic Plan*.

IACC/OARC

- The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee mandated by Congress to coordinate all efforts within the Department of Health and Human Services (HHS) concerning ASD.
- Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.
- The IACC mission is to:
 - Provide advice to the Secretary of Health and Human Services regarding Federal activities related to autism spectrum disorder.
 - Facilitate the exchange of information on and coordination of ASD activities among the member agencies and organizations.
 - Increase public understanding of the member agencies' activities, programs, policies, and research by providing a public forum for discussions related to ASD research and services.
- The Office of Autism Research Coordination (OARC) coordinates and manages the IACC and related cross-agency ASD activities, programs, and policies.

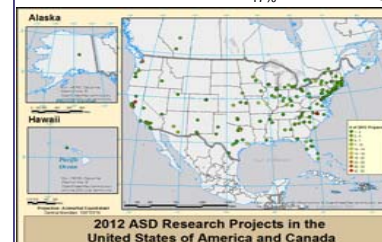
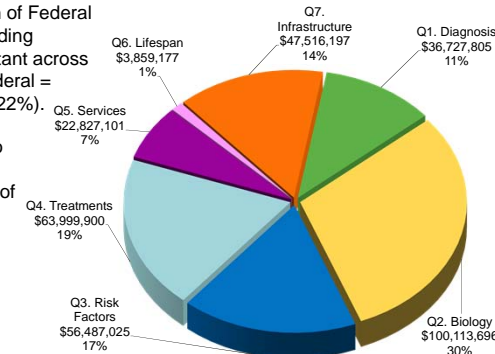
IACC Strategic Plan for ASD Research

- The *IACC Strategic Plan* is organized around seven general topic areas that are represented as consumer-focused Questions (see diagram below). For example, Question 1, "When should I be concerned?" covers the topic of screening and diagnosis.
- Associated with each question is a list of specific long- and short-term objectives. The objectives were created by the IACC to address critical gaps and opportunities they identified in the research landscape.
- The *IACC Strategic Plan* was launched in 2009 and is updated annually. New objectives have been added over the years, with the most recent objectives added in 2011; all subsequent Portfolio Analyses have been coded to this version.



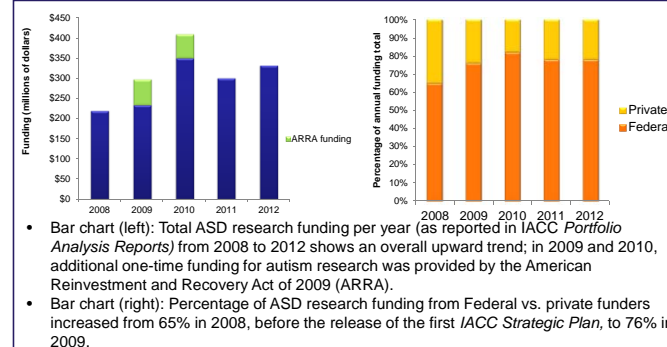
2011-2012 Portfolio Analysis Report Findings

- The estimated investment in ASD research across government and private funders increased slightly from 2011-2012 (2011: \$299,628,985; 1225 projects. 2012: \$331,530,901; 1309 projects).
- The distribution of Federal and private funding remained constant across this period (Federal = 78%, Private = 22%).
- The pie chart to the right shows the distribution of 2012 ASD research funds across the 7 *Strategic Plan* topic areas.



- Map (left): Distribution of ASD research projects across U.S. and Canadian research institutions in 2012

2008-2012 Overview



Summary

- The annual *IACC Portfolio Analysis Report* can be used by Federal agencies and private research organizations to help guide future funding priorities by outlining current gaps and opportunities in ASD research, as well as serving to highlight current activities and research progress.
- In addition to the *Portfolio Analysis Report*, the *IACC/OARC Portfolio Analysis Web Tool*, is also available on the IACC website (see separate poster).

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